RESEARCHING TO CURE EPILEPSY

SPRING 2022

CURE
EPILEPSY™

After losing a loved one, no family should ever have to ask “why?”

BETH LEWIN DEAN
Chief Executive Officer
CURE Epilepsy

★★★★
CHARITY NAVIGATOR
Four Star Charity

Our ongoing efforts to end SUDEP and find a cure for epilepsy have contributed to our Charity Navigator Four Star rating – earned in February 2022 – which recognizes that we exceed industry standards and outperform most charities in our cause.

Death is one of the most difficult realities we face about epilepsy. When people living with epilepsy pass away both unexpectedly and inexplicably, our entire community grieves. Although Sudden Unexpected Death in Epilepsy (SUDEP) is a very real risk of this disorder, thousands of patients and families remain unaware until it’s too late. **SUDEP is the worst possible outcome of epilepsy.**

We believe a world without SUDEP is possible – and we know that research is the key to creating it.

We’ve dedicated this issue of *Researching to CURE Epilepsy* to exploring this complex topic, showcasing promising breakthroughs in the race to end SUDEP. As the nonprofit leader in epilepsy research, CURE Epilepsy pioneered research into SUDEP and led the community in raising awareness and driving it as a research priority. Over nearly two decades, we’ve funded projects that have made measurable strides in identifying SUDEP risk factors, causes, and prevention techniques. In this issue, we’re excited to feature our newest and most promising SUDEP research grants and catch up with one of our first grantees, Dr. Peter Carlen, on his innovative seizure alarm technology.

Through these discoveries, lessons, and powerful real-life stories, we also seek to raise awareness about SUDEP and empower our community with information so that they can mitigate their risk. We take that role seriously, providing year-round education and participating in SUDEP Action Day each October, sharing the latest information on warning signs and mitigation methods.

In these pages, you’ll also learn about ongoing ways we’re raising money for research and creating hope for patients with diverse circumstances and stories. Our second annual **Unite to CURE Epilepsy** virtual event was a huge success, raising over $1.8 million for a cure. We hope you’ll join us this June in our hometown of Chicago for a live benefit featuring even more great entertainment.

As always, we remain grateful for your continued support and optimism. Your dedication and giving spirit have once again enabled us to pursue research during another challenging year, putting us one step closer to curing epilepsy. Through research there is hope.

With continued gratitude,

Beth Lewin Dean
Chief Executive Officer, CURE Epilepsy

AN UNWAVERING COMMITMENT TO ENDING SUDEP

CURE Epilepsy grantees and SUDEP researchers Dr. Alica Goldman and Dr. Jeff Noebels in their laboratory at Baylor College of Medicine.

SUDEP is one of the most devastating but least discussed outcomes of an epilepsy diagnosis. Every year, it steals years of life from children and adults and burdens their families with a lifetime of grief. Every life lost – every year lost – is unacceptable, and this is why the epilepsy community must continue fighting to end SUDEP.

In the wake of losing loved ones to SUDEP, several CURE Epilepsy parents – including Jeanne Donalty (see her Pioneer Spotlight on page 12) – stepped up to make our organization one of the earliest advocates for SUDEP prevention. As the pioneer in SUDEP research, we funded the field's first private research initiative in 2004 and have continued to support top scientists. On the following pages, you will find a snapshot of how we've driven the conversation and outcomes.

SUDEP REFERS TO THE SUDDEN, UNEXPECTED, WITNESSED OR UNWITNESSED, NONTRAUMATIC, AND NONDROWNING DEATH IN PATIENTS WITH EPILEPSY. IT MAY BE SEEN WITH OR WITHOUT EVIDENCE OF A RECENT SEIZURE AND WITH NO CAUSE OF DEATH FOUND ON AUTOPSY.[1]

> "CURE Epilepsy's contribution to understanding the risk of sudden death in epilepsy has been early, sustained, and transformative. From a handful of case reports 20 years ago to over 200 scientific publications in 2021, CURE Epilepsy's support of individual investigators provided the engine to develop advanced basic and clinical collaborations. We all owe CURE Epilepsy our gratitude for its continuing leadership in accelerating this effort."
>
> **JEFF NOEBELS, MD, PHD**
> **BAYLOR COLLEGE OF MEDICINE**

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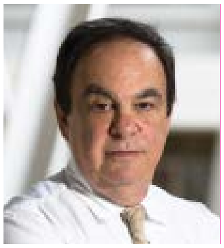
[1] Nashef L, So EL, Ryvlin P, Tomson T. Unifying the definitions of sudden unexpected death in epilepsy. Epilepsia. 2012;53(2):227–33.

20 YEARS OF BREAKTHROUGHS:

THE ENDURING IMPACT OF CURE EPILEPSY FUNDING



Two decades ago, **Dr. Peter Carlen** received a one-year grant from CURE Epilepsy that laid the foundation for his research into seizure detection and electrical neurostimulation. Fast-forward to today, and Dr. Carlen's work has yielded transformational advancements, including the identification of a SUDEP biomarker and the development of a seizure alarm that could potentially prevent SUDEP.

The incredible arc of Dr. Carlen's career highlights the pace of progress in epilepsy research, where discoveries evolve over years and even decades. Through his continued pursuit of a cure, he has meaningfully shaped the prediction and treatment of epilepsy over the last 20 years.

Dr. Carlen's research has always been motivated by a desire to help real people live outside the shadow of epilepsy. As a neurologist and epileptologist, he was inspired by his patients to find a cure. For his first research project, he partnered with mathematician and engineer Dr. Berj Bardakjian and physicist Dr. Houman Khosravani, discovering that seizures could be arrested with brief, low-frequency electrical pulses delivered to brain tissue.

More recently, Dr. Carlen collaborated with Dr. Bardakjian on a project that is shifting their focus from experimental science to direct patient impact. After identifying SUDEP biomarkers in the unique electrical patterns of the electroencephalogram (EEG), they started a company, Neurometrics Technology, to provide patients and caregivers with an alarm system for seizures and SUDEP biomarkers.

"It's humbling to think that without our initial CURE Epilepsy grant 20 years ago, we wouldn't have started this amazing company or discovered the breakthroughs that it was founded on," says Dr. Carlen.

Looking back at Dr. Carlen's legacy of discovery, we are so proud to have funded his 2002 project. We look forward to the additional contributions he will make to epilepsy research – particularly SUDEP – in the years ahead.

> "I've seen the intense suffering people with epilepsy endure. As an epileptologist and a scientist, I'm in a unique position to develop more effective treatments with little to no side effects – a true cure."
>
> PETER CARLEN, MD
> SENIOR SCIENTIST, KREMBIL RESEARCH INSTITUTE AND PROFESSOR, DEPARTMENT OF MEDICINE, UNIVERSITY OF TORONTO

CURE EPILEPSY HAS SUPPORTED

38

SUDEP RESEARCH PROJECTS AND AWARDED

$5.3 MILLION

IN SUDEP GRANTS TO DATE.

CATCHING UP WITH PAST SUDEP GRANTEES

FRANCK KALUME, PHD

SEATTLE CHILDREN'S RESEARCH INSTITUTE

CURE Epilepsy Sleep and Epilepsy Award Grantee, 2017, funded by the BAND Foundation

Dravet syndrome (DS) is a rare, drug-resistant epilepsy that begins in the first year of life in an otherwise healthy infant. In collaboration with Dr. Orrin Devinsky of New York University, Dr. Kalume studied mice with DS, engaging them in an exercise challenge that revealed clear abnormalities with their autonomic nervous systems. Understanding the biological reasons for these irregularities and how environmental changes may adversely affect them could help scientists develop novel methods to reduce seizure-related health consequences, as well as the high risk of SUDEP.

ANNAPURNA PODURI, MD, MPH

BOSTON CHILDREN'S HOSPITAL

CURE Epilepsy Award Grantee, 2016, funded by the Isaiah Stone Foundation

Sudden Infant Death Syndrome (SIDS) is one category of Sudden Unexplained Death in Pediatrics (SUDP), which accounts for more childhood deaths than childhood cancer or heart disease. Dr. Poduri's research reveals a potential link between SIDS and epilepsy- and SUDEP-associated SCN1A gene variants. She and her colleagues recently published a paper providing strong evidence for the role of genetic factors in SUDP, including genes not previously associated with sudden death. Their research findings illustrate the importance of engaging parents of children who passed away to obtain phenotypic and genetic data to help provide families with answers about how their child passed, identify potential concerns for at-risk family members, and improve our understanding and prevention of SUDP.

CURE EPILEPSY'S LEGACY OF LEADERSHIP IN SUDEP RESEARCH

2004

Launched a first-of-its-kind SUDEP research program with first grant to Carl L. Faingold, PhD.

2008

Partnered with the National Institute of Neurological Disorders and Stroke (NINDS) to host the first-ever scientific SUDEP meeting.

2009

Formed the SUDEP Coalition with other leading epilepsy research organizations to facilitate, coordinate, or sponsor individual SUDEP research projects.

2010

Developed the Centers Without Walls concept with NINDS to promote collaborative research to speed the pace of epilepsy research.

2012

Became a founding member of PAME (see page 11) to create broader SUDEP awareness among multiple stakeholder groups.

2017

Awarded the first grants to study the interaction between sleep and epilepsy.

2018

Celebrated CURE Epilepsy grantee Dr. Annapurna Poduri's discovery of a link between an epilepsy gene and Sudden Infant Death Syndrome (SIDS).

2020

Established a partnership with The Cameron Boyce Foundation.

SUDEP FACTS TO DISCUSS WITH YOUR DOCTOR

SUDEP IS THE LEADING CAUSE OF EPILEPSY-RELATED MORTALITY, WITH APPROXIMATELY **3,000 DEATHS ANNUALLY.**[2]

EXPERTS AGREE THAT MANY **SUDEP DEATHS GO UNREPORTED.**

SUDEP HAS RESULTED IN **MORE YEARS OF LOST LIFE** THAN ALS, MULTIPLE SCLEROSIS, AND ALZHEIMER'S DISEASE.[3]

SUDEP CAN OCCUR **DESPITE TAKING MEDICATIONS,** CO-SLEEPING, AND CPR.[6]

1 IN 1,000 ADULTS AND CHILDREN WITH EPILEPSY IN THE U.S. DIES EACH YEAR FROM SUDEP.[4,5]

SUDEP RISK INCREASES TO **1 IN 150** FOR PEOPLE WHOSE EPILEPSY IS NOT CONTROLLED BY MEDICATION.[7]

WAYS TO MITIGATE SUDEP RISK

Gaining control of your seizures greatly reduces the risk of SUDEP. Below are some key strategies:

- TAKE MEDICATION AS PRESCRIBED
- AVOID KNOWN SEIZURE TRIGGERS
- GET ENOUGH SLEEP
- AVOID DRINKING ALCOHOL
- TRAIN FAMILY IN SEIZURE FIRST AID
- CONSIDER NIGHT-TIME MONITORING

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[2] Devinsky O et al. Recognizing and preventing epilepsy-related mortality. Neurology. 2015.

[3] Thurman DJ et al. Sudden unexpected death in epilepsy: assessing the public health burden. Epilepsia. 2014 Oct;55(10):1479-85.

[4] Sveinsson O, Andersson T, Carlsson S, Tomson T. The incidence of SUDEP: A nationwide population-based cohort study. Neurology. 2017 Jul 11;89(2):170-177.

[5] Keller AE, Whitney R, Li SA, Pollanen MS, Donner EJ. Incidence of sudden unexpected death in epilepsy in children is similar to adults. Neurology. 2018 Jul 10;91(2):e107-e111.

[6] Verducci et al. SUDEP in the North American SUDEP Registry. Neurology Jul 2019, 93 (3) e227-e236.

[7] Sveinsson O, Andersson T, Carlsson S, Tomson T. The incidence of SUDEP: A nationwide population-based cohort study. Neurology. 2017 Jul 11;89(2):170-177.

CURE EPILEPSY IS RESEARCHING FOR...

Anthony

At 22 years old, Anthony Maffie was an energetic young man who was busy attending nursing school, caring for people at his local hospital, and pursuing outdoor hobbies. His friends and family never suspected that one morning he wouldn't wake up, having passed away from SUDEP overnight.

Anthony's journey with epilepsy began a month before his 16th birthday, when he experienced his first tonic-clonic seizure. While researching his condition, Anthony's mom, Lisa Maffie, came across the topic of SUDEP. She started a conversation with Anthony's neurologists, but they assured her not to worry.

Over the next several years, Anthony experienced intermittent seizures but was able to control his epilepsy for long stretches with medication. That made it even more shocking when Anthony's brother, Austin, went to wake him up to get ready for a basketball game and discovered him unresponsive in bed.

At the time of his death, Anthony had been seizure-free for 2 ½ years – but looking back, Lisa Maffie recognizes that he had several SUDEP risk factors. Anthony was diagnosed before age 16, experienced convulsive seizures at night, and had a job that left him sleep-deprived. She hopes that more clinicians will start talking with their patients about SUDEP so that they can help prevent this devastating cause of death.

Since Anthony's passing, the Maffie family has chosen to celebrate his life and raise money to prevent SUDEP from affecting others. The Maffies have also joined forces with CURE Epilepsy to raise awareness of SUDEP and help fund research that can lead to a cure. This May, they will host a run/walk in their Massachusetts hometown.

> "Anthony was so full of life – he was a golfer, rugby player, fisherman, hardworking student, and certified nursing assistant at a community hospital. We're so glad we found CURE Epilepsy so that we can honor his legacy while helping other families avoid the tragedy of SUDEP."
>
> **LISA AND BOBBY MAFFIE**
> **ANTHONY'S PARENTS AND EPILEPSY ADVOCATES**

CURE EPILEPSY IS RESEARCHING FOR...

Sean

Everyone who knows Sean Matthew Rabus loves his ear-to-ear smile and infectious laughter. They appeared soon after he was born a healthy baby and continued after he and his family began fighting to cure his epilepsy against all odds.

At 7 months old, Sean started having spasms. His pediatrician said it was just his nervous system developing, but his parents sought a neurologist's opinion. On a Wednesday morning, Sean had an abnormal EEG and was immediately admitted to the hospital. He endured a CAT scan, an MRI, a spinal tap, and blood draws, never crying once. Less than eight hours after his first EEG, Sean was diagnosed with Infantile Spasms (IS) and began taking adrenocorticotropic hormone (ACTH) medication.

The next question was what caused his IS? Initial testing indicated that Sean may have a genetic disorder, and genetic testing confirmed it. Sean has Menkes disease – a copper absorption disorder almost always terminal by age 3.

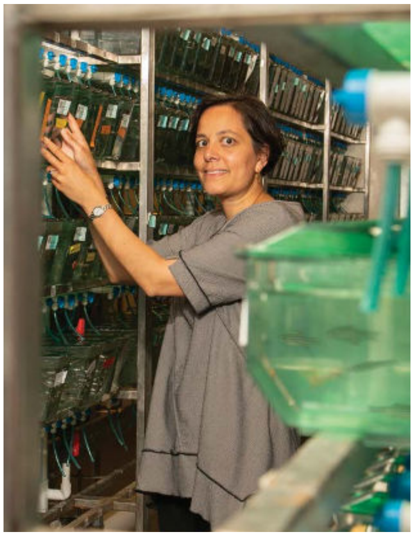
Sean's parents rushed to contact the premier Menkes doctor in the U.S. and the only drug company producing a therapeutic treatment. Sean was granted emergency compassionate access to copper histidine. Still awaiting FDA approval, this medication is the only therapeutic treatment to help kids with Menkes resume development. Sean's IS stopped for a while after his initial treatment but returned later that fall – round two of ACTH. Sean has always been a fighter and once again laughed when his mom gave him daily injections. His smile disappeared while he underwent ACTH treatments – perhaps the most challenging thing for his parents during that time. But the return of his smile in December 2019 showed his never-ending resilience to fight his epilepsy and his Menkes.

Sean is now 3 1/2 years old, and his recent EEG registered no seizures – a major milestone. He loves Curious George, Cars, gear toys, and playing with his best friend and little brother, Danny. He can control his head, he's working on sitting and putting weight into his legs, and he communicates using eye gaze. Sean's parents speak about when, not if, he will talk and walk, believing there's nothing he can't do. Sean works hard every day with his team of therapists; his nanny, Maggie; and his extended family to develop his abilities. There are no organizations dedicated to Menkes research, so his parents are especially grateful for CURE Epilepsy's unwavering commitment to curing seizure disorders, allowing kids like Sean to grow and thrive.

> "Sean's Menkes was caused by a spontaneous genetic mutation – a one in a million chance. No research will change Sean's genes, but CURE Epilepsy's research makes a huge difference. If we can continue controlling his seizures, Seany Matt can continue developing and amazing us daily."
>
> **MAUREEN FLOOD RABUS**
> **SEAN'S MOM AND EPILEPSY ADVOCATE**

YOUR DONATIONS ARE FUELING CRITICAL SUDEP RESEARCH

Thanks to the support of our loyal donors and partners, **CURE Epilepsy has awarded over $5.3 million to fund 38** of the most promising SUDEP research projects worldwide. Since 2004, our efforts have:



- Funded four SUDEP registries and multiple animal models of SUDEP.
- Elevated physician and patient awareness of SUDEP.
- Helped to establish respiratory arrest as a leading cause of SUDEP.
- Revealed the link between SUDEP and genes found in both the brain and heart.
- Helped establish generalized tonic-clonic seizures as a clear risk factor for SUDEP.
- Supported the passing of SUDEP reporting legislation in several states.
- Identified a SUDEP biomarker and the development of a seizure alarm that could potentially prevent SUDEP.

EVERY PROJECT PUTS US ONE STEP CLOSER

Research is the key to preventing this devastating consequence of epilepsy and creating hope for millions of patients and families. CURE Epilepsy is relentless in our search for a cure, and your support is invaluable in funding projects that are changing the landscape.

SUDEP NAMED GRANT FUNDERS

We thank the families and foundations that have generously funded SUDEP research through named grants with CURE Epilepsy since 2004.

The Axelrod Family Award

The BAND Foundation Award

The Cameron Benninghoven Award

The CURE Epilepsy Cameron Boyce SUDEP Research Award

The Christopher Donalty and Kyle Coggins Award

The HOPE4SUDEP Award in honor of Cameron Benninghoven

The Joanna Sophia Foundation

The Henry Lapham Memorial Award

The Maggie Loeffel Award

The Northwestern Dance Marathon Award

The Rock the Block for Pediatric Epilepsy Research Award

The Isaiah Stone Foundation Award

WE NEVER STOP RESEARCHING TO FIND A CURE

CURE Epilepsy is the only nonprofit organization in the United States focused solely on finding a cure for epilepsy, including causes of epilepsy-related mortality, such as SUDEP. Our rigorous review process identifies research projects that leverage cutting-edge science while offering maximum potential benefits to patients. Meet our recent grantees, and learn how they're accelerating discovery and advancing hope for children and adults with epilepsy.

CURE EPILEPSY AWARDS

These two-year, $250,000 awards go to established researchers focused on scientific advances that have the potential to truly transform the lives of people affected by epilepsy.

THE CURE EPILEPSY CAMERON BOYCE SUDEP RESEARCH AWARD

For the second consecutive year, The Cameron Boyce Foundation has partnered with CURE Epilepsy to offer this special award to advance the most promising research into SUDEP. The Cameron Boyce Foundation was established by Victor and Libby Boyce to fund research and honor the legacy of their son, Cameron, who passed away from SUDEP in 2019.

> "We thank CURE Epilepsy for allowing us to participate in this work and for including us in their community. We are confident that by working together, we can make a significant difference in the lives of people living with epilepsy."
>
> **LIBBY BOYCE**
> **CAMERON'S MOM AND EPILEPSY ADVOCATE**

DAVID AUERBACH, PHD

SUNY UPSTATE MEDICAL UNIVERSITY

Cardiac and Autonomic Pathological Markers for Arrhythmias and Sudden Unexpected Death in Epilepsy Patients

THE REALITY

People with epilepsy have a higher prevalence of cardiac electrical abnormalities. Arrhythmias, or irregular heart rhythms, often precede SUDEP.

THE NEED

Patients need to know how to recognize and prevent cardiac conditions that could result in SUDEP.

THE SCIENCE

Dr. Auerbach and his team will use analytical tools that are well-accepted in the cardiac field, but new to the field of epilepsy and SUDEP, to identify epilepsy patient populations at risk of cardiac arrhythmias. His team will also test whether these tools can identify people with epilepsy who later died of SUDEP. This study will form part of a comprehensive SUDEP risk assessment tool based on markers for each of the proposed biological causes of SUDEP, including cardiac arrhythmias.

STEFAN BARAKAT, MD, PHD

ERASMUS UNIVERSITY MEDICAL CENTER

Finding New Therapies for Epileptic Encephalopathies by Employing Knowledge From Rare Genetic Diseases

THE REALITY

Epileptic encephalopathies are severe genetic disorders causing intractable seizures and pronounced developmental delays.

THE NEED

Patients need tailored therapies that directly modulate the biological pathways leading to disease, instead of simply repressing symptoms.

THE SCIENCE

Dr. Barakat and his team will build on his prior studies that have identified various genes involved in biological pathways not previously implicated in epilepsy. For this study, his team will use human cell models and zebrafish to target metabolic processes implicated in these pathways and develop novel therapies for epileptic encephalopathy.

NIGEL PEDERSEN, MD

EMORY UNIVERSITY

Sleep and Epilepsy Interactions – Uncovering Mechanisms

THE REALITY

There is a long-recognized link between epilepsy and sleep-wake states, with many patients experiencing seizures at specific times of day or in relation to sleep.

THE NEED

Patients need to know how they can help prevent seizures associated with sleep-wake states or certain times of day.

THE SCIENCE

Dr. Pedersen's team will directly study electrical activity in parts of the brain that control sleep and wakefulness, as well as brain regions involved in seizures. They will utilize new methods to determine exactly which brain cell types are involved in this strong relationship between sleep-wake and epilepsy.

ASLA PITKÄNEN, MD, PHD

UNIVERSITY OF EASTERN FINLAND

Systems Biology-Derived Treatment of Status Epilepticus and Epileptogenesis After Traumatic Brain Injury

THE REALITY

Traumatic brain injury (TBI) is a major cause of epilepsy in adults.

THE NEED

Patients need new ways to prevent the development of epilepsy after TBI.

THE SCIENCE

Dr. Pitkänen and her team have identified drug-like compounds that might reverse or prevent the harmful effects of gene expression changes caused by TBI. In this study, the team will evaluate whether the most promising of these compounds can prevent the development of epilepsy in an animal model of post-traumatic epilepsy (PTE). The team will also assess whether alleviating sleep disturbances can prevent the gradual process of developing epilepsy.

A BEACON FOR THE EPILEPSY RESEARCH COMMUNITY

CURE Epilepsy is highly visible and highly influential among top epilepsy research and advocacy organizations. Here are a few ways we're collaborating with them to advance innovation for the benefit of all patients and families.

Left to right: CURE Epilepsy Founding Mother Barb Kelly with daughter and board member Marilynn Kelly Gardner and CURE Epilepsy grantee Avtar Roopra, PhD (University of Wisconsin); CURE Epilepsy Founder Susan Axelrod with Chief Scientific Officer Dr. Laura Lubbers; CURE Epilepsy PTE Investigators Vicky Johnson, PhD (UPenn) and Alex Shandra, MD, PhD (Virginia Tech); and CURE Epilepsy industry partners Ruth Suter and Andrea Wilkinson (Zogenix, Inc. (UCB)).

AMERICAN EPILEPSY SOCIETY (AES) ANNUAL MEETING

DECEMBER 2021

The AES Annual Meeting brings together the world's leading medical and research professionals in epilepsy, offering the most extensive epilepsy education and scientific exchange in the field. CURE Epilepsy was involved throughout the event, celebrating new science and helping to facilitate connections that are driving breakthroughs.

- CURE Epilepsy recognized our recent grantees, who are conducting groundbreaking research, during our annual reception.
- CURE Epilepsy Associate Director of Research Lauren Harte-Hargrove, PhD, hosted an investigators workshop titled "Novel Techniques and Models To Identify Epileptogenesis in Post-Traumatic Epilepsy (PTE)." Featuring junior investigators, the workshop addressed what we can learn from clinically relevant animal models of PTE and how new techniques and technologies can help us understand seizure origination following a TBI.
- CURE Epilepsy was recognized as a key source of funding in eight poster presentations highlighting current researchers in epilepsy, including Dr. Victoria Johnson (University of Pennsylvania) and Dr. Jeffrey Loeb (University of Illinois Chicago), who are members of CURE Epilepsy's PTE Initiative.
- CURE Epilepsy Founder Susan Axelrod shared insights during a speech at the Epilepsy Leadership Council (ELC) luncheon. As a keynote speaker, Susan used this opportunity to inspire fellow ELC members to continue its mission of encouraging collaboration to provide better outcomes for those with epilepsy.

PARTNERS AGAINST MORTALITY IN EPILEPSY (PAME) MEETING

PAME is a collaborative effort to advance our understanding of epilepsy-related forms of mortality, especially SUDEP, through dynamic meetings held in conjunction with AES. On December 2, 2021, CURE Epilepsy participated in the 5th PAME meeting in Chicago. With input from clinicians, scientists, health care providers, patients, families, and advocates, PAME continues to spark important conversations, raise awareness, and advance research to prevent death from epilepsy.

pame
PARTNERS AGAINST MORTALITY IN EPILEPSY

CURE Epilepsy is a founding member of PAME and continues to be a leading voice at PAME meetings. Gardiner Lapham, the current chair and a co-founder of PAME, is a former board chair of CURE Epilepsy. She, Jeanne Donalty, and others were instrumental in prioritizing SUDEP research as a key area for CURE Epilepsy.

CURE EPILEPSY IS RESEARCHING FOR...

Wendy

In July 1987, Wendy Veasey was opening her car door on a Wisconsin road when she was hit by a motorcycle and thrown 86 feet. With injuries sustained all over her body, she went into cardiac arrest and was in a coma for three days.

Wendy experienced the first of many seizures after arriving home from the hospital. Her first medication caused an allergic reaction, and she ended up trying nearly 10 different medications. Testing revealed that her seizures traveled to both sides of her brain, so she wasn't eligible for brain surgery.

Dedicated to controlling her seizures, Wendy's doctor encouraged her to participate in a drug study for vigabatrin. Wendy has been free of side effects and tonic-clonic seizures for almost 20 years – yet she pushes for a cure, not just treatment. She continues to share her story with leading epilepsy researchers, most recently at CURE Epilepsy's reception at the 2021 American Epilepsy Society meeting in Chicago.

> “We still don't know enough about who is likely to develop epilepsy after an accident like mine. I'm grateful that CURE Epilepsy continues to search for a cure so that people can return to their lives sooner after TBI.”
>
> **WENDY VEASEY**
> **EPILEPSY ADVOCATE**

AS A RESULT OF HER TRAUMATIC BRAIN INJURY (TBI), WENDY DEVELOPED EPILEPSY.

Jeanne Donalty

MOM OF CHRISTOPHER DONALTY,
WHO PASSED AWAY FROM SUDEP IN 2002

More than 20 years after her son's death from SUDEP, Jeanne Donalty remains a staunch advocate for difficult conversations that can save lives. Learn why she's spent the last two decades tirelessly working to drive critical funding for SUDEP research.

You became an epilepsy advocate because of your son, Chris. Tell us about the amazing young man he was.

Everything about Chris was big – his stature, his personality, his voice, and his heart. He was 6 feet, 3 inches tall. He was incredibly smart, graduating 10th in his high school class of over 500 students and making the dean's list each semester at Stetson University, where he was a senior. He had a gift for humor, and he would debate anyone on just about any topic.

Chris loved sports. He rooted for the Duke basketball team, the Notre Dame football team, and his beloved New York Yankees. He was also an athlete. He intended to try out for the Stetson University baseball team and dreamed of a major-league career.

What was Chris's journey with epilepsy, and how did it affect you and your family?

Chris was perfectly healthy until fourth grade, when his school called and told me he had fainted. I got a similar call when he was in eighth grade. Then, right before Chris's senior year of high school, his friends found him unconscious outside the restroom. A neurologist finally confirmed he had epilepsy.

Chris had to give up his driver's license for six months and was put on Dilantin. After three seizures his freshman year of college, his doctor added Depakote. Chris hated that drug. It affected his short-term memory and made him tired and nauseated. When the doctor switched him to Lamictal, Chris stopped reporting seizures – but we later found out that he was hiding them from us. Chris died from SUDEP on February 21, 2002, a few months shy of his college graduation.

Chris's death has had an indelible impact on me, his dad, and his two older sisters, Alison and Lauren. For a long time, we were terrified to confront how his death changed our family. No one asked Chris's sisters how they felt about his death. There is always a hole there, but we choose to honor his life rather than focus on our loss.

Chris's doctor never talked to your family about SUDEP, and as far as you know, he never discussed it with Chris. Why is it important for every doctor to talk with every epilepsy patient about SUDEP?

The day he died, Chris had gone to his girlfriend's apartment to study while she attended class. When she arrived home, Chris wasn't breathing. She performed CPR, but it was too late. If Chris had known that he could die from SUDEP, he wouldn't have gone to the apartment alone.

I've spoken with dozens of doctors over the last 20 years, and too few are talking about SUDEP. They don't want to tell patients they could die from epilepsy when the risk seems low and they're still researching what causes SUDEP and how to prevent it.

HELP US END SUDEP

This spring, give the gift of hope by donating to fund SUDEP research. To make a gift in memory or honor of a loved one, please scan the QR code to the left.

The problem is that SUDEP isn't rare – it's just not as common as other outcomes. Everyone who's lost a loved one to SUDEP wishes they had known about it, no matter how difficult the conversation. I tell all families to educate themselves thoroughly on SUDEP to help prevent tragedy.

You helped to drive CURE Epilepsy's pioneering focus on SUDEP research. How did that focus materialize?

After we attended Chris's funeral, memorial service, and graduation ceremony, we didn't want his death to be the end of his story. I got connected with CURE Epilepsy Founder Susan Axelrod. The first thing she said to me was "Tell me about Chris." I knew then that CURE Epilepsy had the right focus.

That fall, I attended the American Epilepsy Society meeting with several CURE Epilepsy mothers. I was determined to speak with doctors and motivate them to tell their patients about SUDEP, but I encountered resistance – when doctors saw me walking down the hallway, they turned around and went the other way to avoid being hassled. Luckily, SUDEP was gaining momentum among a small number of physicians, researchers, and families – although it would take several years before other epilepsy organizations and federal agencies, including the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC), began to make SUDEP a priority. For a while, CURE Epilepsy was out there on its own.

CURE Epilepsy has awarded several Christopher Donalty Award grants to SUDEP researchers. Tell us about those projects and why they are so meaningful to Chris's legacy.

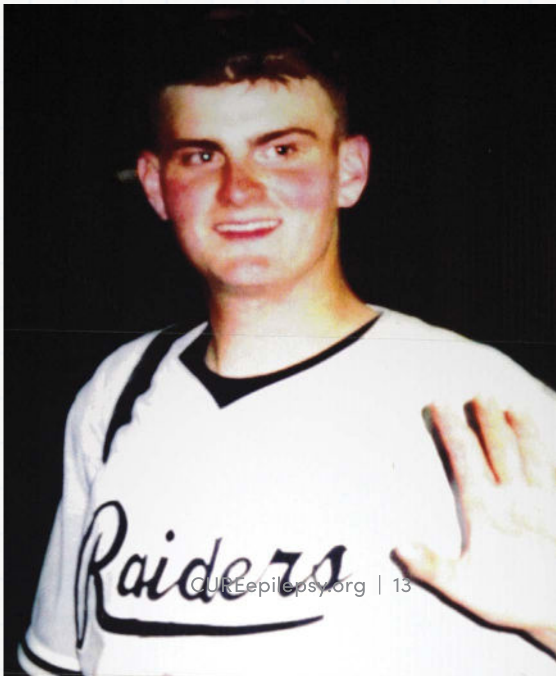
When CURE Epilepsy awarded its first SUDEP research grant in 2004, the organization wasn't focused on SUDEP research quite yet – Dr. Carl Faingold's project just happened to be on the topic. CURE Epilepsy named the award after Chris and then started funding SUDEP projects annually. Dr. Pedro Irazoqui's SUDEP implant research award was also named after Chris. Both researchers have pictures of Chris on their desks. They pursue this research because they're inspired by real people's stories. That's why when I talk about Chris, I want people to know just as much about his life as his death.

CURE Epilepsy's research into SUDEP requires continued support from partners and donors. What are the best ways you've found to raise awareness and funding?

The driving force behind advances in SUDEP awareness has been a grassroots effort driven by SUDEP-affected families, including my own. Our first fundraiser for CURE Epilepsy earned $170,000 in 2003. We hosted an event every other year until 2013, raising a total of $1.5 million.

Donating to CURE Epilepsy is a direct and ongoing investment in a cure, and every effort helps – from galas to lemonade stands. The research projects CURE Epilepsy has funded have unlocked critical clues about the role of the heart, lungs, and serotonin in SUDEP. With the support of the entire epilepsy community, I believe that one day, we will solve the SUDEP puzzle.

> "The driving force behind advances in SUDEP awareness has been a grassroots effort driven by SUDEP-affected families, including my own."
>
> **JEANNE DONALTY**



EPILEPSY RESEARCH: WATCH, LISTEN, AND LEARN

CURE EPILEPSY CARES EVENTS

Conversations About Research in Epilepsy & Seizures

Listen to recent CURE Epilepsy CARES events

One of the best ways to learn about new developments is to hear directly from those who are leading them. During CURE Epilepsy CARES events, patients and families get insights and answers directly from medical professionals and researchers about key topics:

- Current treatments and emerging therapies
- Surgical options and devices
- Clinical trial participation
- Managing epilepsy

CURE EPILEPSY CARES NYC

NOVEMBER 6, 2021

This local event featured researchers from some of New York City's top institutions.

ZACH GRINSPAN, MD
Weill Cornell Medicine

PADMAJA KANDULA, MD
Weill Cornell Medicine

LOUISE BIER, MS, CGC
Columbia University

CURE EPILEPSY CARES VIRTUAL

NOVEMBER 19, 2021

This nationally broadcast event featured epilepsy experts from the San Francisco area.

BRENDA PORTER, MD, PHD
Stanford University

ADAM NUMIS, MD
University of California, San Francisco

MICHAEL ROGAWSKI, MD, PHD
University of California, Davis

MARTHA MORRELL, MD
Stanford University

UNDERSTANDING EPILEPSY ONLINE RESOURCE

This resource, made possible through the generous support of SK life science, was created to help people with epilepsy, their caregivers, and their loved ones manage their seizures through knowledge. Visit **CUREepilepsy.org/understanding** to learn about epilepsy basics, available treatment options, COVID-19 updates, and more.

WATCH OUR WEBINARS

We believe everyone should have access to cutting-edge epilepsy discoveries explained in an easily comprehensible way. One of our recent webinars discussed the impact of cardiac function in SUDEP.

SUDEP & THE HEART: A MULTI-SYSTEM APPROACH TO UNDERSTANDING ELECTRICAL DISTURBANCES

David Auerbach, PhD
Assistant Professor of Pharmacology
at SUNY Upstate Medical University

There is strong evidence of the association between cardiac abnormalities, particularly cardiac arrhythmias (irregular heartbeat), playing a role in SUDEP. In fact, studies have found mutations in genes associated with cardiac arrhythmias in 15% of SUDEP cases. This webinar allows people with epilepsy, their families, and the broader community to learn:

- How altered cardiac function may lead to SUDEP.
- How inherited neuronal or cardiac diseases may lead to electrical disturbances in the brain and heart.
- Why it is critical for the epilepsy community to holistically understand biological changes that ultimately cause SUDEP.

WANT MORE WEBINARS?

Recent CURE Epilepsy webinars also include *Post-Traumatic Epilepsy and Cognitive Training* and *Diagnosis, Treatment, and Management of Non-Epileptic Seizures*. Visit **CUREepilepsy.org/webinars** to view past recordings or register to attend upcoming events.

LISTEN TO THE *SEIZING LIFE*® PODCAST

The *Seizing Life*® podcast series is one of our primary ways of educating patients, families, and the public. Join us to learn about the daily challenges and triumphs of living with epilepsy as well as the latest information on key topics, such as SUDEP.

SUDEP: WHAT TO KNOW AND WHAT TO DO

Elizabeth Donner, MD
Director, Comprehensive Epilepsy Program
at The Hospital for Sick Children

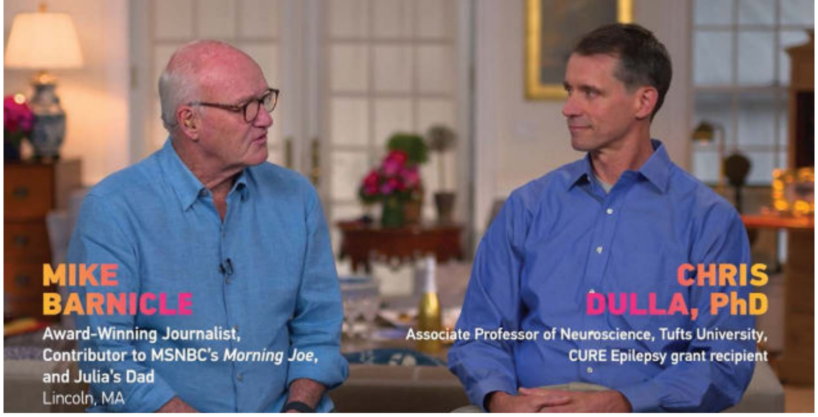
Listen as former CURE Epilepsy grantee Dr. Donner explains what SUDEP is, what we do and don't know about it, how it can occur, who's most at risk, and how to reduce risk factors.

> "The hesitancy to talk about SUDEP for many years was related to people feeling like there's nothing we can do. People with epilepsy and their families have the right to know all the risks of their disorder, the same way we do for heart disease and cancer."
>
> DR. ELIZABETH DONNER

SEIZING LIFE®

WANT TO LEARN MORE?

Recent *Seizing Life*® episodes also include a two-part series discussing infantile spasms and the impact of PTE on veterans. Check out the full series at **CUREepilepsy.org/seizinglife**.



UNITE to CURE Epilepsy

TENACITY. DISCOVERY. HOPE.

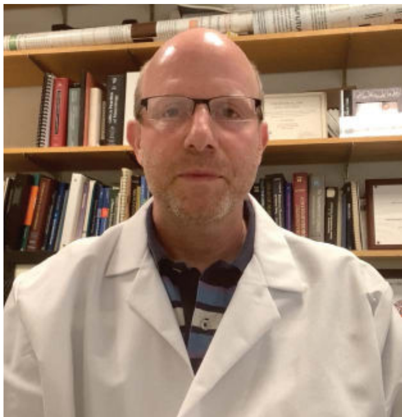
SEPTEMBER 17, 2021

Our second annual virtual event brought the global epilepsy community together again for an evening of lively entertainment, moving stories, and promising research updates. Special guests included award-winning journalist Mike Barnicle, James Beard Award-winning chef Rick Bayless, Rock & Roll Hall of Famer Nils Lofgren, and Broadway star Miguel Cervantes.

OVER $1.8 MILLION RAISED TO FIND A CURE FOR EPILEPSY

OVER 1,000 PEOPLE CAME TOGETHER TO MAKE THIS EVENT A SUCCESS

OVER 40 WATCH PARTIES HOSTED AND VIEWERS IN 35 STATES



Top to bottom: Nils Lofgren; Tina Sacks; Daniel and his parents, Paula and David Allbeck; Erin Laslow and her daughter, Hadley; Kelly Cervantes and Chef Bayless; Dr. Eric Marsh (UPenn)

CURE EPILEPSY AT THE NYSE

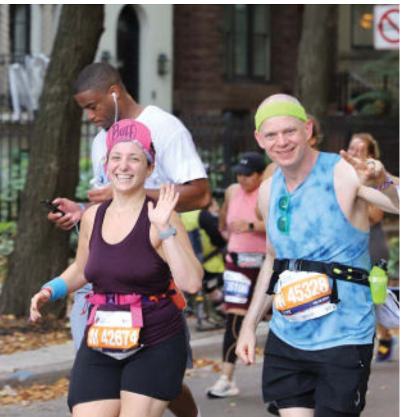
NOVEMBER 1, 2021

We kicked off Epilepsy Awareness Month by ringing the New York Stock Exchange Closing Bell®.

> **"People invest in the stock exchange to create the promise of a better future for themselves and their families. CURE Epilepsy invests in talented researchers and novel science to help find cures for epilepsy and foster the promise of a better future for those living with epilepsy."**

BETH LEWIN DEAN
CEO, CURE EPILEPSY

Top to bottom: Beth Dean; De'Maryo and Danita Platt, with sons Gabriel and Michael; Miguel Cervantes and son Jackson



CURE EPILEPSY RUNS FOR A CURE

Team CURE Epilepsy runners raced 26.2 miles through our beautiful hometown neighborhoods and all five NYC boroughs to find a cure for the 3.4 million Americans affected by epilepsy.

BANK OF AMERICA CHICAGO MARATHON

OCTOBER 10, 2021 | $9,750 RAISED

TCS NEW YORK CITY MARATHON

NOVEMBER 7, 2021 | $29,293 RAISED

Top to bottom: Laura Sambrookes-McQuade (Chicago Marathon), Jason and Ashley Hughes (Chicago Marathon), Roi Trawon (NYC Marathon)

CURE EPILEPSY CHAMPION ELISSA MOORE SPREADS CHEER FOR A CURE

DECEMBER 2021 | NEARLY $13,000 RAISED

For the second year in a row, this CURE Epilepsy Champion converted her annual holiday card into a fundraiser for CURE Epilepsy in honor of her son Cormac, who was diagnosed at age 9 with an intractable genetic epilepsy that causes frequent seizures.

REAGAN MONAST'S 10TH BIRTHDAY INSPIRES DECADE OF GIVING

OCTOBER 15, 2021 | NEARLY $6,000 RAISED

Just before she turned 2, Reagan was diagnosed with epilepsy and cerebral palsy. For her 10th birthday, she and her family challenged their community to help raise money for a cure for epilepsy by running, jogging, or walking 10 miles in 10 days for 10 years.

FUGETT MIDDLE SCHOOL STUDENTS DOMINATE EPILEPSY

NOVEMBER 2021 | $4,018 RAISED

Middle-schoolers from West Chester, Pennsylvania, sold "FMS DOMinates Epilepsy" wristbands and purple ribbons in honor of special education teacher Elizabeth Scolis's 4-year-old grandson, Dominic "DOMinator" Rosini, who has a rare form of epilepsy known as Doose syndrome.

$380,000+

RAISED BY OUR 2021 CHAMPIONS

CURE EPILEPSY IS RESEARCHING FOR...

Roi

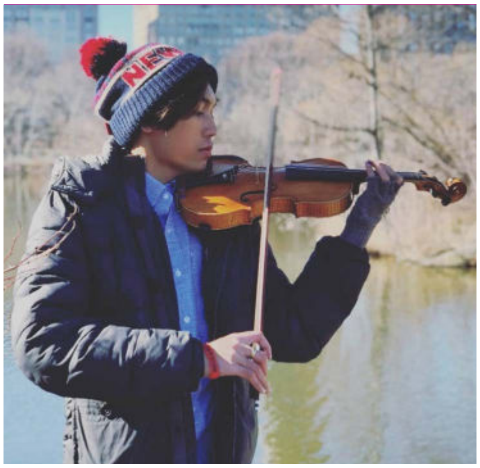
Roi Trawon is a man of many interests. He's a math lover, currently pursuing a master's degree in statistics. He's a runner who competed in the 2021 NYC marathon for Team CURE Epilepsy. And he's a distinguished violinist who won the Very Special Arts International Young Soloists Competition for musicians with disabilities.

Roi first experienced twitching at age 10 while attending boarding school in his native country of the Philippines. Looking back, he now recognizes these twitches as absence, or petit mal, seizures, a diagnosis he didn't receive for several more years. Even as they progressed to a few times a week, Roi didn't think they were a big deal. It wasn't until his parents noticed him collapsing and dropping objects that Roi saw a neurologist, who diagnosed him with epilepsy.

At first, Roi struggled to accept his diagnosis, given the unsettling way epilepsy is often portrayed in the media. But his friends were supportive, assuring him that he was a normal person who was free to live his life.

Determined to follow his dreams, Roi earned his bachelor's degree in the Philippines in 2016 at age 20 and then moved to the U.S. to study music. Roi still experiences seizures but works hard to prevent them by taking his medication, identifying his triggers, and staying as healthy as possible. His many interests continue to take him to new places, introduce him to new people, and help him find strength.

ROI'S DISABILITY IS EPILEPSY, BUT HE'S NEVER LET IT STOP HIM FROM PURSUING HIS PASSIONS



> "The only disability in life is the lack of perseverance. I do not ever plan to let epilepsy hinder my dreams in any way."
>
> ROI TRAWON
> EPILEPSY ADVOCATE AND TEAM CURE EPILEPSY RUNNER

2021 DONOR HONOR ROLL

We are profoundly grateful to the thousands of individuals and organizations whose gifts have helped advance epilepsy research and our mission to find a cure. While space prevents us from acknowledging every donor, our gratitude is limitless. Thank you.

The following are donors who gave $500 or more between January 1 and December 31, 2021. We have made every effort to ensure the accuracy of this report. If your name has been omitted or misprinted, please accept our sincere apologies and notify the CURE Epilepsy staff at **info@CUREepilepsy.org** or **(312) 255-1801**.

CUREepilepsy.org/2022spring

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Our Champions are grassroots fundraisers who help us raise critical research funds and raise awareness for epilepsy.

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Beth Scolis
Amanda Vasquez
Nick Watka
Alexandra Williams

We’d also like to thank our 2021 Team CURE Epilepsy fundraisers and Facebook fundraisers.

THANK YOU, VOLUNTEERS

CURE Epilepsy's work depends on all of our volunteers. We thank each of you, including those who serve on our committees. CURE Epilepsy external research professionals and our Lived Experience Council members kindly volunteer their time and expertise to ensure the science we fund has the highest potential impact in the epilepsy community. We do not list their names to maintain the integrity of our grant review process.

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The New York Friends of CURE Epilepsy are a group of dedicated volunteers committed to advancing our mission through their awareness and fundraising efforts in the New York area.

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CURE EPILEPSY COMMUNITY ADVISORY COMMITTEE (CECAC)

CECAC members are directly connected to the epilepsy community as both patients and caregivers. They help us reflect the community's voice in all that we do – including strategic planning, educational programs, fundraising and awareness events, communication strategies, and more.

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WE WON'T STOP RESEARCHING UNTIL WE PUT AN END TO SUDEP AND FIND A CURE FOR THE MILLIONS OF PEOPLE LIVING WITH EPILEPSY.

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